parkinson's australia

National Advocacy · Connection · Awareness

NDIS Evidence Advisory Committee Consultation September 2025

Executive Summary

Parkinson's Australia Submission to the NDIS EAC - on EPs & Smart Home Appliances for people with Parkinson's

At Parkinson's Australia, we deeply understand the profound impact that NDIS supports have on the lives of people living with Parkinson's disease (PwP). Parkinson's is associated with significant costs to individuals and to society.

The necessity of having an Accredited exercise physiologists (AEP) and smart appliances in PwP's plans cannot be overstated. To have these supports in the short term means that the overall cost to society in the long run is much smaller.

Our submission, the scientific literature, peak bodies like ESSA and our young onset Parkinson's supporting case studies aim to highlight the need for these supports to maintain independence for longer and reduce costs overall.

We urge policymakers to embrace these recommendations, as they represent a pivotal step towards reducing reliance on others like more costly support workers, gardeners, weekly cleaners, not to mention the costs of falls and hospitalisation if balance and core strength is not maintained.

- **Parkinson's is the fastest growing neurological condition in the world, incidence rates increase 4% per year. (1)**
- **There are more than 1,100 Aussies under 65 who develop young onset each year. Only 16% of all those living with YOP have an NDIS approved plan. (2)**
- **Parkinson's is impacting on our economy and healthcare systems at a cost of over $10 billion each year. (3)**
- **The mean annual cost per person to the health care system was $32,556 AUD. The burden to society was an additional $45,000 per annum per person with Parkinson's. (4)**

Recommendation 1: Formally include Accredited Exercise Physiology (AEP) as a core support for people with Parkinson's, with flexibility for frequency based on clinical need.
Accredited exercise physiologists are trained to design and develop exercise programs tailored to Parkinson's symptoms, goals, and outcomes. These individualised plans can help manage muscle stiffness, tremors, postural instability, and gait difficulties. By addressing these issues, AEPs can significantly improve physical function, confidence in walking and quality of life including gut health, sleep and mental wellbeing. AEPs also contribute to falls prevention, thereby lower risk of injury and emergency interventions, keeping PwP out of hospital and reducing the need for in-home safety monitoring.

Recommendation 2: Recognise Smart Home Appliances as legitimate assistive technology, particularly for people with fatigue, mobility limitations, and cognitive challenges. This results in the need for in-home support services for cleaning and incurs a one-off costs with long-term benefits (e.g., $600 for a robotic vacuum vs. ongoing cleaning support).

Recommendation 3: Establish clear guidelines for reasonable expenditure limits on smart devices to ensure equitable access and cost control.

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Parkinson's Australia is the national voice & advocate representing over 150,000 people living with Parkinson's, their families, carers, researchers, and health professionals. We connect communities & promote awareness to support those affected in living well & independently.

Parkinson's Australia represents one of the most vulnerable groups in NDIS – those diagnosed with a, progressive neurodegenerative, incurable condition that has debilitating motor (movement) and non-motor symptoms (e.g.sleep, continence, vision, fatigue, apathy).

Parkinson's Australia is concerned that the removal of these NDIS supports (EP & Smart Home Appliances) will not accommodate the needs of a person managing complex neurodegenerative conditions such as Parkinson's.

Introduction

Drawing on peer-reviewed literature, lived experience, and insights from Parkinson's Australia, Exercise & Sport Science Australia peak bodies, and the Young Onset Parkinson's Exchange, we demonstrate that these supports are not only clinically beneficial but also cost-effective over time. Their continued inclusion will maintain independence, reduce long-term care costs, and improve quality of life for those living with a greatly fluctuation condition where fatigue and motor symptoms impact everyday tasks.

Understanding Parkinson's

There are over 150,000 people living with Parkinson's in Australia. Fifty Australians are diagnosed every day. Young Onset Parkinson's makes up 10 to 20% of all people living with Parkinson's. They are diagnosed in their 20s to 50s. (5)

Parkinson's disease is a whole-body, neurodegenerative, progressive condition that affects movement, mood, sleep, voice, vision and the gastrointestinal system.

The pathophysiology of Parkinson's is complex and involves multiple chemical messengers (neurotransmitters), resulting in many changes to a person's normal functioning and everyday life (6).

In Parkinson's, nerve cells in the brain called neurons slowly break down or die. Many Parkinson's symptoms are caused by the loss of neurons that produce chemical messengers in the brain. The main messenger involved is called dopamine, which regulates mood and movement.

Decreased dopamine leads to irregular brain activity. When 60% to 80% of these dopaminergic neurons are lost, this causes the hallmark movement symptoms of slowness, rigidity, and one-sided tremor.

People with Parkinson's also lose a chemical messenger called norepinephrine that controls many automatic body functions, such as blood pressure and temperature regulation (7).

Early signs of Parkinson's include a reduced or loss of sense of smell, unexplained depression and/or anxiety, sleep issues, chronic constipation and handwriting changes.

There are an estimated of 30,000 people under the age of 65 living with Parkinson's in Australia. (5) Though they are living with a life-limiting disability, less than 10% are on NDIS as at 2021 numbers in the NDIS report.(2) In 2022, 39.4% of people with disability aged under 65 reported needing more formal assistance than they were receiving. This highlights a significant gap in support services, including access to schemes like the NDIS. (8)

Clinical Evidence & Benefits of AEPs

Exercise is an essential part of Parkinson's symptom management. It is the only intervention currently shown to slow disease progression, improve motor and non-motor symptoms, and enhance neuroplasticity (9).

Regular engagement with AEPs ensures tailored, safe, and effective exercise programs that address Parkinson's-specific challenges such as gait, balance, rigidity, fatigue, constipation and apathy.

Peer-reviewed studies confirm:

- Exercise improves gait, strength, and balance (10).
- It reduces falls and hospital admissions (11).
- It enhances mood and cognitive function (12).

These outcomes translate into reduced reliance on acute care services and delayed progression to higher levels of support. It is essential for early intervention and wellbeing.

Because of the need for an AEP on a PwP care team, a number of resources have been developed in partnershp with ESSA: https://www.parkinsons.org.au/information-hub/exercise-physiologist/

- **Falls are common in people with Parkinson's, with a high incidence rate of 40% to 70%. (13)**
- **Exercise is second only to medication in terms of effectiveness in slowing the progression of Parkinson's disease. (14)**
- **Regular exercise can improve gait, balance, tremor, flexibility, strength, and coordination. (15)**
- **Exercise can reduce the risk of falls, which is particularly important for people with Parkinson's who are more prone to falling. (16)**
- **Exercise has been shown to decrease depression and anxiety, enhance memory, and reduce fatigue. (17)**

Lived Experiences & Benefits of AEPs

"Support offered through exercise physiology/allied health has improved my quality of life and I believe allowed me to retain independence and confidence as a mother, social worker and community member."
— Woman living with YOP

"Having an AEP on my care team provides me with a tailored, early intervention exercise program that addresses my particular symptoms and one-sidedness. It helps me achieve my goals for physical fitness and mobility while reducing pain, stiffness and bradykinesia."
— Man living with YOP

"The EP takes some of the mental load off me by programming appropriate workouts and tracking my progress... I struggle with fatigue and apathy... but I strive to make that appointment, whether I feel motivated to go or not."
— Woman living with YOP

These testimonials highlight how AEPs also help overcome Parkinson's-specific barriers to exercise, such as apathy and fatigue, and provide structure and accountability that self-directed programs cannot.

Cost Savings

- Reduced falls and hospital admissions.
- Delayed need for higher-level care and support.
- Improved ability to remain employed and socially engaged.

Lived Experience of someone living with YOP for >30 years - benefits of AEPs

"Since the beginning of my NDIS plan, and after many years of severely reduced mobility and the inability to walk or exercise due to the later stages of Parkinson's disease, I have spent the last four years on a positive road to rehabilitation, stability, and improved quality of life — all thanks to my Exercise Physiologist Specialist (deidentified to my AEP).

I was diagnosed with early-onset Parkinson's disease in my 20s, and by the age of 50, after more than 35 years living with the condition, I was in the advanced stages. My symptoms included severe loss of strength, agility, coordination, and cognition, along with painful dystonic spasms that had resulted in multiple hospital admissions. My ability to walk and move independently had become extremely limited, and my overall health and wellbeing were deteriorating.

When my NDIS plan was approved, my long-term GP referred me to (an AEP) highly recommending her for her extensive experience with Parkinson's and complex neurological conditions. This referral has been one of the most beneficial and transformative interventions in my healthcare journey.

In addition to her specialist work addressing the motor and non-motor symptoms of Parkinson's disease, (my AEP) has also played a critical role in helping monitor, manage, and communicate the changes in my cardiovascular health over the last two years.

During this period, I have experienced two separate episodes of pericarditis with effusion (a year apart), as well as episodes of tachycardia and dangerously fluctuating blood pressure — common complications that can be made worse by Parkinson's disease and its medications.

(My AEP) has the clinical knowledge and experience to understand how Parkinson's affects autonomic regulation and cardiovascular function. She regularly and accurately monitors my heart rate and blood pressure before, during, and after sessions, adjusting exercise intensity and technique accordingly. She also maintains clear, professional communication with my neurologist, Parkinson's nurse, and GP, providing valuable updates that have helped guide ongoing medical management and medication adjustments.

This high level of interdisciplinary collaboration has been vital in preventing hospitalisation, detecting early signs of cardiovascular distress, and ensuring my exercise program remains safe and effective despite my complex medical picture.

Impact of Exercise Physiology

Through her tailored and evidence-based Exercise Physiology programs, (my AEP) has guided me with a pragmatic and compassionate approach, focusing on all aspects of my condition. My individualised program includes:

- Boxing and coordination training
- Balance and fall-prevention exercises
- Strength and resistance training
- Cardiovascular and endurance work
- Cognitive and dual-tasking activities

Lived Experience Advanced YOP continued...

Her deep understanding of Parkinson's pathophysiology and its impact on the nervous, muscular, and cardiovascular systems has ensured my sessions are not only safe but therapeutically effective.

Outcomes and Achievements

The results of my ongoing Exercise Physiology sessions with (my AEP) have been truly life-changing:

- My strength, agility, balance, and coordination have returned.
- My cognition, multitasking, and daily function have dramatically improved.
- My painful spasmodic episodes are now minimal.
- My blood pressure and cardiovascular symptoms are more stable and closely monitored.
- My confidence, mood, and independence have all improved.

As a direct result, I have remained safely at home, avoided further hospital admissions, and maintained my independence — key goals of both my NDIS plan and my personal wellbeing.

The Importance of Exercise Physiology for Parkinson's Disease

Exercise Physiology is essential for individuals living with Parkinson's disease and related complex medical conditions. It is far more than exercise — it is targeted, evidence-based therapy that:

- Maintains strength, balance, and mobility to prevent falls and injuries.
- Improves cardiovascular health, blood pressure regulation, and endurance.
- Delays progression of symptoms and secondary complications.
- Enhances cognition, mental health, and quality of life.
- Reduces hospital admissions and the need for early residential care.

Without regular Exercise Physiology, many people with Parkinson's experience rapid decline in both physical and cognitive function. In my case, it has been the most effective therapy for managing symptoms, improving function, and preserving independence.

Conclusion

(My AEP) has become an indispensable part of my NDIS healthcare team. Her professionalism, medical knowledge, compassion, and dedication have been instrumental in helping me regain stability and control over my health and daily life.

I strongly advocate for Exercise Physiology to remain a core, ongoing funded support under NDIS plans for people living with Parkinson's disease and other complex neurological conditions. It is not just a service — it is a medical and therapeutic necessity that enables participants to live safely, independently, and with dignity.

— Woman living with YOP

One size does not fit all. Exercise should be carefully prescribed for each individual with Parkinson's disease, taking their impairments, disease severity, fall risk and goals into account. As an individual's disease progresses over time, their exercise program will need to be reviewed and updated to meet their changing needs and ensure their safety. (18)

Evidence & Benefits of Smart Home Appliances

Smart Home Appliances, such as robotic vacuums and mowers, smart lighting, voice-controlled assistants, medication reminders and smart doorbells offer practical solutions to the physical and cognitive challenges of Parkinson's. They reduce the burden of daily tasks, enhance safety, and support independent living.

Peer-reviewed studies confirm:

- Robot vacuums, available with or without mopping capabilities, can reduce effort by cleaning automatically, making them a good choice for people with mobility challenges. (19)
- Smart home assistive technologies can reduce the need for support services, improve quality of life, and provide cost-benefit advantages for people with disability. (19)
- They are particularly beneficial for people with mobility and cognitive challenges. (20, 21)
- Smart home and communication technologies reduce activity limitations and participation restrictions, supporting people with complex needs. (23)

These studies confirm that smart appliances are not just "convenience devices" but legitimate assistive technologies that reduce reliance on paid support, increase safety, reduce carer burden and maintain the PwP's independence, especially when living alone.

Lived Experiences & Benefits of SHAs

"I work long days on shift and struggle with fatigue... If I didn't have the smart vacuum and mop set up I would struggle to keep my floors clean."
— Person living with YOP

"I can control the lighting in my house with my voice which has been helpful when my general movement has been compromised... I can also call or contact someone using voice commands if I have a fall/injure myself and require help."
— Person living with YOP

"It is a one-off expense... I can let the vacuum do its job every day if I want to and that leaves me more energy to maintain the rest of my home."
— Person living with YOP

These testimonials highlight how SHAs also help overcome Parkinson's-specific barriers to everyday tasks. It also shows these devices are not luxuries, but essential tools that mitigate PwP disability-related barriers to promote and maintain independence, safety and a fully functioning home.

Cost Savings

Smart home items help PwP live independently in a safe and convenient manner for relatively small cost and set-up.

Over 3–5 years, a robotic vacuum can save thousands compared to ongoing cleaning support, while also reducing reliance on external services. They:

- Reduced need for in-home support services for e.g. cleaning and safety monitoring.
- Lower risk of injury, falls and emergency interventions.
- Are a one-off cost with long-term benefits (e.g., ~$1000 for a robotic vacuum vs. ongoing cleaning support costs).

FINAL SUMMARY: Parkinson's Australia Submission to the EAC - September 2025 review of EP & Smart Home Appliances

We want to iterate that we understand the profound impact that an AEP can bring to the lives of people living with Parkinson's. Evidence shows that working with an AEP can improve mobility, balance, strength, mood, and overall quality of life for people living with Parkinson's. Targeted exercise also reduces freezing of gait, improves walking speed, and enhances posture. Regular, tailored exercise programs may even help slow disease progression and reduce symptom severity. Furthermore:

- Falls are common in people with Parkinson's, with a high incidence rate of 40% to 70%. (1)
- Exercise is second only to medication in terms of effectiveness in managing symptoms. Exercise is the ONLY thing shown to slow the progression of Parkinson's disease and improves neuroplasticity. (2)
- Regular exercise can improve gait, balance, tremor, flexibility, strength, and coordination. (3)
- Exercise can reduce the risk of falls, which is particularly important for people with Parkinson's who are more prone to falling due to their stiffness, balance and gait changes. (4)
- Exercise has been shown to decrease depression and anxiety, enhance memory, and reduce fatigue. (5)

The information in this submission about AEPs is endorsed by Exercise & Sports Science Australia (ESSA).

Assistive technologies like smart home appliances help PwP to remain independent and safe. The alternatives to a smart home appliance would be more costly e.g. support worker/cleaner coming weekly to vacuum and mop versus a once-off cost for a robot to do the same thing; or the potential of a costly fall when someone is too fatigued and stiff to clean the floors safely on their own.

Recommendation 1: 1. Formally include Accredited Exercise Physiology (AEP) as a core support for people with Parkinson's Disease, with flexibility for frequency based on clinical need.
Accredited exercise physiologists are trained to design and develop exercise programs tailored to Parkinson's symptoms, goals, and outcomes. These individualised plans can help manage muscle stiffness, tremors, postural instability, and gait difficulties. By addressing these issues, AEPs can significantly improve physical function, confidence in walking and quality of life including gut health, sleep and mental wellbeing. AEPs also contribute to falls prevention, thereby lower risk of injury and emergency interventions, keeping PwP out of hospital and reducing the need for in-home safety monitoring.

Recommendation 2: Recognise Smart Home Appliances as legitimate assistive technology, particularly for people with fatigue, mobility limitations, and cognitive challenges. This results in the need for in-home support services for cleaning and incurs a one-off costs with long-term benefits (e.g., $600 to $1000 for a robotic vacuum vs. ongoing cleaning support).

Recommendation 3: Establish clear guidelines for reasonable expenditure limits on smart devices to ensure equitable access and cost control.

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